Chapter 10

Developing State Capacity for Integrating Genomics into Chronic Disease Prevention Programs: An Update

Introduction

During July 2003, the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) of the Centers for Disease Control and Prevention (CDC) established cooperative agreements with state health departments in Michigan, Minnesota, Oregon, and Utah to strengthen programs for genomics and chronic disease prevention. The purpose of initiating these agreements was to assist states in developing or expanding their capacity for genomics leadership as well as to integrate genomic tools and knowledge into chronic disease programs for improved health outcomes (*www.cdc.gov/genomics/activities/fund2003.htm*).

Accomplishments and Activities for 2004

During January 2004, an initial meeting of the genomics program directors was held in Atlanta, Georgia. The purpose of this meeting was to encourage communication about the progress, plans, and potential collaboration of the four funded states and the three CDC-funded Centers for Genomics and Public Health. *For more information on this topic, see Chapter 9, University Centers for Genomics and Public Health–Michigan, North Carolina and Washington.* One year later, each state has reported the following progress.

Michigan Department of Community Health: Examples of Genomics in Practice

(*www.MIGeneticsconnection.org*)

The goal of the Michigan Department of Community Health (MDCH) Genomics Program is to improve chronic disease prevention efforts and health outcomes through the enhanced use of genomics in core public health functions. The Michigan Genomics and Chronic Disease Prevention cooperative agreement is divided into the following focus areas:

- Michigan Builds a Solid Foundation: Establishing Infrastructure.
- Creating New and Analyzing Old: Using Cancer Registry Data for Genomic Epidemiology.
- Building a Knowledge Base: Increasing Genetic Literacy.

Michigan Builds a Solid Foundation: Establishing Infrastructure
MDCH has increased organizational and operational capacity for integrating genomics into a variety of public health practice activities and selected policy issues. A major accomplishment in 2004 was the creation of the MDCH core genomics team, including permanent state personnel and one contractual employee. A genomics workgroup with representation from each chronic disease program meets quarterly and functions as an extension of the core team.

The MDCH cancer genetics consultant facilitates the Michigan Cancer Genetics Alliance (MCGA). MCGA is a unique statewide public/private partnership with 150 members that provides leadership, education and advocacy for cancer genetics in Michigan (1). The MCGA celebrated its first anniversary in 2004. Major accomplishments of the MCGA include:

- Providing assistance with the development of MDCH cancer risk assessment modules for breast, colon, and prostate cancer.

- Creating an online provider directory and MCGA Web page (*www.migeneticsconnection.org/cancer*).

- Considering Medicare and Medicaid reimbursement for cancer genetic testing.

- Taking initial steps toward collection of statewide data on inherited cancer.

- Creating and disseminating a member newsletter (*www.michigancancer.org/Word/MICaGenAlliance-newsl-Winter04.doc*).

Creating New and Analyzing Old: Using Cancer Registry Data for Genomic Epidemiology
Although family health history is one example of an important genomics tool, the Michigan Genomics program is also exploring other innovative methods of using genomics for chronic disease risk assessment. The Michigan Cancer Registry is a statewide, population-based reporting system that contains cancer incidence and mortality data for reported cases since 1985. Hospitals and laboratories are required by law to file reports on all diagnosed malignant tumors. To determine the feasibility of an inherited cancer surveillance system, multiple genomics projects were initiated in 2004 using the Cancer Registry data, including a review of the following:

- Number of early onset cases (before 50 years of age) by age of diagnosis and age of death for specific cancers (breast, ovarian, colorectal, pancreatic, kidney, stomach and prostate).

- Frequencies of rare malignant tumors with possible hereditary links by **ICD-O** and **morphology codes**.

- Documented family history information by Cancer Registry tumor registrars in abstracted charts at hospitals targeted for quality assurance visits.

Building a Knowledge Base: Increasing Genetic Literacy
Because genomics is a new term, efforts must be made to raise public awareness, stimulate interest, and increase the public's knowledge of this field. In Fall of 2004, the Detroit Science Center hosted the "Genome" exhibit sponsored by Pfizer. For part of this public museum exhibit, the MDCH genomics team members produced a poster exhibit representing genomics and public health through the lifecycle. The genomics coordinator also participated in a daylong event for the public about family history and chronic disease prevention in conjunction with Wayne State University.

In response to the national family health history initiative launched by United States Surgeon General, Dr. Richard H. Carmona (2), the MDCH genomics team created a short electronic newsletter entitled Family History and Your Health. The first in a series, this newsletter was distributed to Michigan public libraries and included a healthy lifestyle message to the public from Michigan's first Surgeon General, Dr. Kimberlydawn Wisdom (3). Librarians expressed great interest in both the newsletter and its message; consequently, libraries will be sent packets of family history and chronic disease prevention information to disseminate to the public.

Minnesota Department of Health (MDH) Chronic Disease Genomics Project: Project Highlights for Year 2004

(*www.health.state.mn.us/divs/hpcd/genomics/index.html*)

The MDH Chronic Disease Genomics Project has focused on the following activities:

- Minnesota Statewide Focus Groups.

- Conference: Genomics and the Connection to Public Health Practice.

- Including genomics in the Minnesota Comprehensive Cancer Control Plan.

- Including genomics in regional chronic disease workshops.

- Genomics presentations at statewide conferences.

ICD-O
The International Classification of Diseases for Oncology is used principally in tumor or cancer registries for coding the site (topography) and the histology (morphology) of neoplasms, usually obtained from a pathology report.

Morphology code
A five-digit code ranging from M-8000/0 to M-9989/3. The first four digits indicate the specific histological term. The fifth digit after the slash (/) is a behavior code that indicates whether a tumor is malignant, benign, in situ, or uncertain.

Minnesota Statewide Focus Groups

An important objective of the Minnesota Department of Health (MDH) Chronic Disease Genomics Project is to develop a sustainable education program on genomics for the public health workforce in Minnesota. To assess need and create a foundation for developing an educational program, the Minnesota Department of Health (MDH) conducted focus groups among key stakeholders throughout the state in May 2004. The purpose of these focus groups was to assess learning needs, priority areas, and concerns among Minnesotans in order to help shape future project activities related to genomics. Five telephone focus groups were conducted with 23 participants from state and local public health departments, healthcare providers, educators, genetic counselors, community leaders, researchers, and healthcare advocates.

The most frequently mentioned issues were:

- Concerns about ethical, legal, social, and public policy issues, including the need for legislator education about these issues.
- Need for education about genomics in health education, health promotion, and disease prevention; health professionals in particular want to integrate practical information about genomics into their activities.
- Capacity building for genomics education, which is perceived as one of the roles for MDH.
- Concern that genomic research will increase health disparities.

When asked what role MDH should play in responding to these issues, participants responded that MDH should:

- Educate a variety of audiences.
- Provide support and technical assistance to public health practitioners for integrating genomics into existing programs.
- Maintain a safe repository for genetic and genomic information.

Overall, the strongest response regarding the role MDH should play was to educate public health practitioners, healthcare providers, legislators, and the public in the following ways:

- Public health practitioners want information regarding practical, cost-effective ways to integrate genomics into their activities, along with easily articulated concepts to explain why genomics are important.

- Health care providers want education regarding family history as a way to stratify risk and make recommendations for screening and testing.

- Participants felt that legislators need accurate information regarding genetic testing and workplace/health insurance issues in order to pass informed non-discrimination laws.

- Practitioners believe the public needs information regarding family health history and balanced, accurate information regarding new discoveries – as opposed to media hype.

The full report can be accessed at *www.health.state.mn.us/divs/hpcd/genomics/*.

Conference: Genomics and the Connection to Public Health Practice
The focus groups conducted in June 2004 helped inform the content and format of Minnesota's first Genomics in Public Health conference held in November 2004. The attendees at this conference were from a wide spectrum of disciplines involved in improving public health in Minnesota.

Three roundtable work groups were held to discuss chronic disease, gene/environment interaction, and ethical, legal, and social issues. The purpose of the roundtables was to identify concrete steps for integrating genomics into public health. Additionally, the participants were asked to complete a survey to define needs and perceptions and concerns related to genomics at completion of the sessions. A report summarizing participant responses helped inform Minnesota's second conference in May 2005. This report is available at: *www.health.state.mn.us/divs/hpcd/genomics/index.html*.

All of the presentations, including a panel discussion and the question and answer session, were video- and audio-taped and recorded on DVD media. The DVDs will be distributed to a variety of audiences in Minnesota and will also be made available online for other audiences. A summary of the conference that includes the conclusions of the roundtable discussions is available at: *www.health.state.mn.us/divs/hpcd/genomics/genomics%20conference%20summary.pdf*.

Genomics Included in the Minnesota Comprehensive Cancer Control Plan
The Minnesota genomics project coordinator co-led a work group to develop strategies for including genomic tools and information in cancer prevention and early intervention activities in the state. Genomic strategies, especially family history and mechanisms for referral and public education, were incorporated as strategies and action steps in all areas of the plan.

At the second Minnesota Cancer Planning summit held in November 2004, action plans were developed for implementing the cancer plan strategies. Family history was identified in many of these action plans as being important in estimating risk, identifying the population burden of cancer and at-risk populations, screening for cancer, and developing prevention and screening messages. The opportunity to integrate genomics in many health care sectors across the state in relation to cancer prevention, screening, and treatment may serve as a model for the integration of genomics in other chronic disease prevention activities. The Minnesota Comprehensive Cancer Plan 2005-2010 is available at *www.cancerplanmn.org/*.

Genomics Included in Regional Chronic Disease Workshops
Minnesota has prepared state plans to address chronic diseases including diabetes, cardiovascular disease, cancer, and arthritis. Representatives from these plans conducted four regional workshops around the state with which to share their plans and encourage partnerships. The Minnesota genomics project health educator was invited to participate in the workshops, which focused on educating and raising awareness of genomics in relation to chronic disease.

The activities consisted of a formal presentation, providing a genomics display with handouts, providing a packet of educational materials, and taking a tour of the various genomic resources and educational tools available online. This was an opportunity to increase capacity and demonstrate the relevance of genomics and family history to chronic disease and to network and build relationships with the public health workforce of Minnesota.

Genomics Presentations at State Professional Conferences
The Minnesota genomics project coordinator and health educator have presented on genomics at several statewide and regional conferences and have received positive reviews. These presentations have addressed genomics and cancer, the role of genomics in preterm labor and birth, nutrigenomics, genomics and MCH issues, and genomics and health disparities. Several of these presentations are available on the Minnesota Chronic Disease Genomics Project website at *www.health.state.mn.us/divs/hpcd/genomics/*.

Oregon State Genetics Program: Genomics and Public Health

(*www.oregongenetics.org*)

The genomics integration effort in Oregon is currently focused on the following activities and goals:

- Integrating genomics into chronic disease programs using the **Stages of Change** model.
- Integrating family history data into population-based surveillance systems.
- Partnering with the Oregon Comprehensive Cancer Control Plan.

Stages of Change (The Transtheoretical Model)
The Stages of Change are different stages that help identify where a person, program or organization is in the process of changing behavior.

Integrating Genomics into Chronic Disease Programs Using the Stages of Change Model

A primary component of the Oregon Genetics Program effort to integrate genomics into public health practice is the creation of a model process to guide integration of genomics into chronic disease program activities. The Genetics Program is currently working with a draft model integration process based on Prochaska and DiClemente's Stages of Change Model, also known as the transtheoretical model (TTM) of behavioral change(4,5). This draft model was created after assessment activities revealed that Oregon's chronic disease programs (e.g., Diabetes, Comprehensive Cancer Control, and Asthma) were at different stages of readiness (i.e., precontemplation, contemplation, preparation, action, or maintenance) to begin using genomics tools in program activities. In the months to come, Genetics Program staff will refine the model and begin working with chronic disease programs to pilot the process.

Integrating Family History Data Into Population-Based Surveillance Systems

This year, Oregon Genetics Program staff added family history-related questions to the 2005 Oregon Behavioral Risk Factor Surveillance System (BRFSS) and the Oregon Toddler Survey (TOTS), a longitudinal follow-up survey to the Oregon PRAMS (Pregnancy Risk Assessment Monitoring System).

The BRFSS family history questions are designed to ascertain health care provider practices and recommendations based on patients' family histories. In addition, questions estimating the prevalence of the population with a family history of diabetes were included. The results will help the Genetics Program work more effectively with health care providers to increase the collection and use of family history information in health care settings. These data will also help identify populations at high or moderate risk of developing diabetes, target public health interventions, and therefore make it possible for the program to use limited resources more efficiently.

TOTS data may be useful in identifying children at increased risk of asthma based on a positive family history. Targeted prevention will then seek to reduce environmental risk factors (such as allergens, cigarette smoke, and air pollutants). TOTS also included questions pertaining to the family history of diabetes. These data will add to knowledge about the relationship between family history of diabetes and risk of developing gestational diabetes.

Collaboration with Oregon Partnership for Cancer Control
The Genetics Program has successfully joined the Oregon Partnership for Cancer Control in the development of the Oregon Cancer Control Plan. Genetics Program staff facilitated the inclusion of genetics information in the Cancer Plan. The population-based focus of the genetics content will be on common, low-penetrance genes that contribute to cancer risk and the interaction of these genes with environmental and behavioral risk factors. The few known cancers that are significantly affected by well-characterized, single-gene mutations (like *BRCA1* and *BRCA2* mutations), will be noted without special emphasis. Family history of cancer will be emphasized as a prevention tool, whereas population-based genetic testing will not. Lastly, the place of appropriate genetic counseling in a comprehensive cancer system will be addressed, as will the ethical, social, and privacy issues surrounding the collection and disclosure of genetic information.

Utah Department of Health: Chronic Disease Genomics Program
(*http://health.utah.gov/genomics*)

The Utah Department of Health (UDOH) Chronic Disease Genomics Program (CDGP) is striving to increase understanding and integration of genomics into public health practice. The CDGP has undertaken a variety of activities to accomplish this goal, including:

- Building public health leadership capacity.
- Educating the public health workforce.
- Exploring the use of family history as a genomic tool.
- Collecting population-based data.

Building Public Health Leadership Capacity
The CDGP has engaged a variety of genetic and public health professionals in developing the leadership necessary for integrating genomics into public health programs. Several strategies have been utilized, including:

- Forming an internal genomics work group consisting of approximately 35 professionals from several departments at the UDOH. Subcommittees have been formed and are implementing work plans related to education, data, and policy issues.

- Forming the external Chronic Disease Standing Committee under the Utah Genetics Advisory Committee to advise the UDOH on genomics policies and activities and update the Utah State Genetics Plan.

- Developing strategies for integrating genomics into the Utah Diabetes Prevention and Control Program, Utah Cancer Control Program, Utah Cancer Action Network, and Utah Asthma Program.

Educating the Public Health Workforce

The CDGP targeted the public health workforce with education and training efforts; the goal of these efforts was to promote understanding of the role of genomics in chronic disease. These education and training activities included the following:

- Assessing genomic knowledge and attitudes as well as appropriate delivery methods of genomics education of 120 UDOH staff.

- Developing and conducting Genomics 101 presentations for approximately 240 public health professionals to increase knowledge and interest levels.

- Drafting a report on current website genomics resources and gaps in those resources for public health professionals as well as for policy makers, health care providers, and the public (6).

Exploring the Use of Family History as a Genomic Tool

The UDOH has extensive experience using family history in chronic disease prevention. From 1983 through 1999, a family history program, the Family High Risk Program (FHRP) or Health Family Tree Project, was used to identify families at high-risk for chronic diseases throughout Utah and provide them with follow-up care.

An assessment was conducted from October 2003 through April 2004 to evaluate the success of the FHRP, during which budgets were reviewed, along with the effectiveness of intervention strategies, perceived successes, barriers and challenges during program implementation, and feasibility of developing new family history programs. Interviews were conducted with former FHRP staff and program materials collected as part of this assessment. A report on the assessment

results was prepared with recommendations for consideration when developing future family history programs, including recommendations for:

- Funding.
- Staff and participant training.
- Partnerships and collaborations.
- Program materials and methods of delivery.
- Legal implications.
- Program leadership.
- Program evaluation.
- Follow-up interventions.

A written report was published on the findings and is available at *http://health.utah.gov/genomics/familyhistory/fhrp.html* (7).

Population-Based Data Collection

The CDGP has assessed or added genomics and family history information to several population-based data collection systems, including:

- *Behavioral Risk Factor Surveillance System (BRFSS)*. Questions were added to assess knowledge, attitudes, and beliefs about the link between family history and disease as well as how much time the public would be willing to spend completing a family history.
- *Utah Population Database (UPDB)*. The UPDB contains genealogy, cancer, driver's license, birth and death, census, and Health Care Financing Administration records. A literature review and discussions with genetic epidemiologists and bioinformatics specialists were held to determine its usefulness for public health genomics.
- *Utah Cancer Control Program (UCCP)* breast and cervical cancer screening enrollment forms. Family history data have been collected by the UCCP for several years; however, it has yet to be analyzed. The data will be analyzed in conjunction with the UCCP to determine the risk ratios for women diagnosed with breast cancer based on a positive or negative family history.

- *Childhood Diabetes Registry* at the Utah Diabetes Center. The registry assesses the incidence and prevalence of diabetes among Utah youth. It contains a section on family history that asks participants, which, if any, first- and second-degree relatives have had diabetes.

Summary of the States' Activities

These four funded states have demonstrated that genomics can be incorporated into public health chronic disease programs. The staff from these states have established infrastructure, built new partnerships, educated the public health workforce about genomics, assessed the integration of genomics into population-based surveillance, and applied family history as a screening tool to identify populations at increased risk of disease in order to more effectively target prevention messages. The progress these states have made and continue to make can serve as a model for other local, state, and regional health departments as they begin to incorporate genomics into public health programs.

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